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Hoarding disorder has finally arrived, but many challenges lie ahead

In 2010, the DSM-5 Obsessive-Compulsive and Related Disorders Sub-Workgroup recommended the inclusion of hoarding disorder as a new mental disorder in the diagnostic system[1]. Following an expert survey[2], a field trial[3], and a period of public consultation, the new disorder was approved for inclusion in December 2012.

Unlike other proposed changes in DSM-5, the separation of hoarding disorder from obsessive-compulsive disorder (OCD) was met with wide support from both colleagues and patients, who largely felt that the OCD label did not accurately reflect their patients' and their own experiences, respectively.

The uncontroversial acceptance of hoarding disorder can be further ascribed to a number of factors, including the recognition that: a) most patients' symptoms cannot be easily attributable to other mental disorders (including OCD); b) there are a number of important differences between hoarding disorder and OCD with respect to phenomenology of the symptoms, onset and course of the disorder, and neural correlates, among others; c) patients are less likely to respond to evidence-based treatments for OCD[4]; d) hoarding is a prevalent problem affecting persons of both genders and across different cultures[5]; and e) the risk of pathologizing normal behaviour (i.e., normative collecting) is low. The planned inclusion of hoarding disorder in the ICD-11[6] is a welcome addition, which will result in a truly global recognition of this disabling condition.

Individuals with hoarding disorder experience persistent difficulties discarding or parting with possessions, regardless of their actual value. This is due to a perceived need to save the items and distress associated with discarding them. This results in the accumulation of possessions that congest and clutter active living areas and substantially compromise their intended use, causing clinically significant distress or impairment. These symptoms must not be attributable to another physical or mental disorder.

Most people with this disorder excessively acquire items that they do not need or for which no space is available, and typically experience distress if they are unable or are prevented from acquiring items (excessive acquisition specifier). A substantial proportion of sufferers lack insight into their difficulties and are reluctant to seek help for their problems (insight specifier). Other common features of the disorder (not required for diagnosis) include indecisiveness, perfectionism, avoidance, procrastination, difficulty with planning and organizing tasks, and distractibility. Some individuals live in various degrees of unsanitary conditions (*squalor*), that may be a logical consequence of severely cluttered spaces and/or related to planning and organizing difficulties. Persons with the disorder may experience conflicts with neighbours or landlords, and legal proceedings regarding housing evictions or loss of custody of children are not uncommon.

Hoarding disorder affects at least 1.5% of men and women[5]. Most patients usually come to the attention of services when they are in their 50s, but the symptoms may first emerge much earlier, during adolescence. Symptoms typically start interfering with the individual's everyday functioning by the mid-20s, and cause clinically significant impairment by the mid-30s[7]. A progressive worsening of symptoms is typically reported over each decade of life[7]. Once symptoms begin, the course of hoarding is often chronic, with few individuals reporting a waxing and waning course[7]. As expected from a newly recognized disorder, the causes of hoarding disorder are largely unknown, but twin studies suggest that both genetic and environmental risk factors are important[8]. Anecdotal links between material deprivation (e.g., childhood poverty) and hoarding have received no support in the literature.

The diagnosis is usually made on the basis of a direct interview to establish whether the person meets the diagnostic criteria. Because hoarding may not always be the initial reason for consultation, clinicians often need to ask direct questions such as "Do you find it difficult to discard or part with possessions?" or "Do you have a large number of possessions that congest and clutter the main rooms in your home?". A home visit is recommended for the assessment of clutter, impairment, and associated risks. If a home visit is not feasible, the clinician should try to gather additional information from reliable informants, such as a spouse or relative (with the patient's consent). This is particularly important for persons with limited insight, because they may underestimate the extent and consequences of their difficulties. The evaluation should include a thorough risk assessment. Attention should be paid to potential fire hazards, the risk of clutter avalanches, the presence of rodent or insect infestation, and unsanitary living conditions that pose a risk to health. In addition, it is important to establish whether other vulnerable persons (e.g., children, elderly people) live with the person who hoards.

Few treatment studies have specifically included individuals fulfilling DSM-5 criteria for hoarding disorder and, therefore, the evidence to guide treatment choice is incomplete. Currently, the intervention with the strongest evidence base for the disorder is a multicomponent psychological treatment

that is based on a cognitive behavioural model[9]. The intervention includes: office and in-home sessions; motivational interviewing methods to address ambivalence about therapy; education about hoarding; goal-setting; organizing, decision-making and problem-solving skills training; exposure to sorting, discarding, and not acquiring; and cognitive strategies to facilitate this work. This intervention has been evaluated in a few controlled clinical trials with promising results. However, the outcomes are modest and the long-term prognosis unclear[10].

While the official recognition of hoarding disorder as a *bona fide* mental disorder is a huge step in the right direction, numerous challenges lie ahead, some related to the disorder itself and others to the limited research into effective treatments and service development. Some patient-related challenges include that many sufferers have limited insight into their difficulties and they actively or passively resist intervention. Even patients with good insight are deeply ashamed and feel stigmatized, so may still not seek help for their difficulties.

Since the disorder was included in DSM-5, research has been slow. Current treatment options are very limited and only available in a handful of university clinics worldwide. The disorder is frequently underdiagnosed. When correctly diagnosed, colleagues have limited or no referral options. Regular OCD or anxiety disorder clinics are ill-equipped to handle intensive behavioural interventions requiring home visits over extended periods.

These challenges can only be met with substantial investments in research on key strategic areas: prevalence and cost of illness studies; improving detection and reducing stigma; treatment development; service development; and development of legislative frameworks to help reconcile the rights and needs of the patients (who need but may not want help) with those of dependents (e.g., children), neighbours, or landlords who may be adversely affected by the disorder.

David Mataix-Cols, Lorena Fernández de la Cruz
Centre for Psychiatry Research, Department of Clinical Neuroscience, Karolinska Institutet, Stockholm, Sweden

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